Understanding Perinatal Bereavement in the Setting of Unexpected Loss: A Comprehensive Literature Review

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Abstract

Perinatal loss can be a life-changing, devastating event for families who experience miscarriage, stillbirth or an unexpected fetal diagnosis leading to death. Grief is an individual process experienced in the setting of loss that has no time frame or measure. For families given an unexpected prenatal diagnosis or experiencing death of an infant, grief can be more distressing and traumatic than other grief reactions. To look at bereavement issues from the perspective of the patient can give insight into the complexity of grief itself and its clinical presentation to better meet the specific needs of families experiencing perinatal loss. This integrative review of literature aims to investigate the characteristics of bereavement and grief responses in the setting of perinatal loss. There has been little work done on the integration of grief into individuals' and couples' lives after a perinatal loss. The goal of learning more about this process is to contribute to a growing body of research that could lead to the development of evidence based interventions to support the well-being of individuals and couples who are grieving after experiencing perinatal loss. How we care for families during times of birth and death speaks to our values and care for all people across the lifespan.

Key words: perinatal loss, bereavement, miscarriage, stillbirth, unexpected diagnosis, grief

Preface

One Saturday afternoon, in the coastal town of Belfast, I watched sweat pearl at Arielle's temples as she spoke. Occasionally a rusted pick-up truck drove by, a sailboat in tow from the rocky waters at the bottom of the hill. We could hear the tires on the thick, hot tar. She'd left her husband and two of her children at home to tell a story, she said she hadn't really shared for a while. She tugged at the cap of the Desert Spring water bottle and fondled the tissues I left on her side of the table along with cough drops and a consent form. It was mid-summer in mid-coast Maine and she had come to record her birth story in my near empty studio at the intersection of Main and High St. in downtown Belfast where frigid water from the Atlantic permeated the bay.

"I made a painting about it. And I'm not an artist, I'm a writer. "Arielle leaned back in the wooden chair, its creaking documented by the audio recorder placed between us. "One of my biggest fears when I was pregnant was stillbirth." They hadn't wanted another baby. But he came anyway and they welcomed him. Arielle bought matching pajamas for her two-year-old daughter and the baby they were now excited to be expecting. Knit hats, diapers, slippers for winter. That was the hardest part, packing away the clothes he would never wear. "We named him before he died." She dragged her hand across her waist line, recounting the moment she realized he'd stopped moving, his untethered hand brushing at her solar plexus. She took a deep breath and told me she woke up one morning and she just knew. She didn't feel pregnant anymore, like the baby had evaporated into thin air. They gave birth to him at home, "If I couldn't have the baby I so wanted, I could at least have the birth I wanted." They buried him in a small wooden box made by a neighbor. They snowshoed out into the woods, the tiny coffin on a sled behind them. We felt awful leaving him there alone." Arielle's voice tugged reluctantly over that last word. Alone.

"And then we got in the car and we were hungry but it felt weird to go out to eat. But I mean, what do you after you bury your child? What do you do that day?" (Weatherby & Bywater, 2011).

Introduction

Birth is a normal physiological event that is inherently life giving and life threatening. Birth, like death, like healing, comes with unique considerations and risks depending on environmental, social and genetic factors. It is a tender time when the veil between life and death is transparent. Perinatal loss can be a life-changing, devastating event for families who experience miscarriage, stillbirth or an unexpected fetal diagnosis leading to death. Grief is an individual process experienced in the setting of loss that has no time frame or measure but that often, eventually subsides in acute emotional pain and becomes integrated (Moore et al, 2011). For families given an unexpected prenatal diagnosis or experiencing death of an infant, grief can be more distressing and traumatic than other grief reactions. Self- blame and suicidal ideation are symptoms of increased distress related to grief (Zetumer, 2015). For individuals or families who do not experience a grief reaction, interventions may not be necessary (Hutti, 2013). It is important to consider the nuances of grief and to not generalize the bereavement process. To look at bereavement issues from the perspective of the patient can give insight into the complexity of grief itself and its clinical presentation to better meet the specific needs of families experiencing perinatal loss.

Background

Approximately 15-20% of pregnancies in the United States end in miscarriage (fetal death before 20 weeks gestation). Miscarriages most often occur in the first trimester, or three months of a pregnancy. Stillbirth occurs when a fetus dies in utero or during labor after 20 weeks of gestation. In the United States 1%, nearly 25,000 babies a year are stillborn. Even with the increase of medical technology, these numbers have remained somewhat stable in recent history.

To draw a more comprehensive picture of perinatal bereavement and its variety of origins, it is important to include an unexpected diagnosis of a fetus. Research supports that an unexpected outcome can prompt a grief response like those expressed after losses by death. (Matthews et. al, 2015).

In this review of the literature, perinatal bereavement is used as an umbrella concept that covers the experiences and expression of loss such as but not limited to grief, mourning and adaption, will be investigated in the loss-settings of miscarriage, stillbirth and unexpected fetal diagnosis. (Peters et al, 2015) Understanding the unique qualities of perinatal bereavement is as important as ever as these losses affect a significant portion of the population. There are relatively few if any interventions specifically developed for this population and process. Caring for families inappropriately during this time may cause unnecessary harm and prolonged grief (Peters et al, 2015).

Methods

Using the keywords developed by careful investigation of this topic, an initial search was performed in three leading research databases, PubMed, CINAHL and PsycInfo. PubMed yielded 7,589 articles. The search was refined to include only papers written in the past ten years, published in academic journals subject to peer review and that addressed the key focus areas of this reviews. This refined the results to 162. Of these 162 abstracts, 10 were selected to be read. CINAHL yielded 1,308 related papers. Filters added to look at papers only citing human research and within the past 10 years narrowed the search to 258 papers. After an initial reading of abstracts, 5 were selected for this review. PsycInfo yielded 912 papers and after being controlled under the same parameters listed above, 104 abstracts were reviewed and 4 papers selected for

inclusion. The final 11 papers referenced in this article were included because they examine one or more of the following: loss expression associated with stillbirth, miscarriage or unexpected diagnosis of a fetus, the definition of prenatal loss and bereavement, patient experiences with loss during pregnancy and childbirth, tools for providers caring for the bereaved in perinatal settings.

Search Terms: (Grief or grieving or bereave* or bereft or lose or losing or lost or cope or coping or mourn* or distress* or adaptation) AND (Infan* or newborn or perinatal or prenatal or fetal or fetus or baby or babies or gestation* or postpartum or "post-partum" or prepartum or "pre-partum" or antepartum or "perinatal loss") AND ("Still birth" or stillbirth or stillborn or "infant mortality" or "infant death" or "unexpected diagnosis" or "unexpected outcome" OR "fetal death" OR "spontaneous abortion" OR miscarr* or abnormalit*[title/abstract] or "birth defect" or "birth defects" or malform*) NOT "fetal growth retardation"[mesh]

Findings: Defining Perinatal Bereavement

There is a bounty of thorough research on grief, bereavement, depression and anxiety as evidence by the several thousands of articles mentioned above. A great deal of research treats grief associated with perinatal loss. However, a great deal remains to be learned about perinatal bereavement and appropriate interventions for caring form women and their partners during and after a loss. The goal of learning more about this process is to contribute to a growing body of research that could lead to the development of evidence based interventions to support the well-being of individuals and couples who are grieving after experiencing perinatal loss. A second aim is to give tools and resources to health care providers including nurses to improve standards of care for grieving families in acute care settings and/or when they return to this setting for

subsequent care. “Nurses assist couples in distinguishing between uncomplicated grief, complicated grief, and depression, and make appropriate referrals” (Moore et al., 2011).

A gap in the research is evident regarding the definition of perinatal bereavement. Often it is defined conveniently within the scope of a study or research topic but it is not always comprehensive. Perinatal bereavement is often implicitly defined within the context of an article or study and usually specified as the grief reactions that follow a loss by death. The implied meaning does not include other types of loss, such as giving up an infant for adoption, the birth of a less than normal infant, a less than hoped for birth experience, or infertility (Fenstermacher et al., 2013). Loss that triggers grief can occur without death and instead by unexpected outcome.

Fenstermacher and colleagues (2013) noted the inconsistency in conceptual meaning and perceive it as a threat to the validity of measurement tools for perinatal bereavement. They argue that this inconsistency also contributes to incongruent theoretical definitions. Although defining perinatal bereavement in a globally relevant way may continue to pose a challenge, there are many qualities unique to perinatal losses that we can understand from parents and providers who navigate these cloudy waters. To better understand these qualities, we must dive deeply into the literature, review validated research and read patient and provider narratives.

Grief Theories

One of the most colloquially known models of loss expression is Elizabeth Kubler-Ross’s five stages of grief. The five stages include: denial, anger, bargaining, depression and acceptance. In healthcare settings today, this model is often utilized. A preliminary search in the same databases listed earlier showed 4 related articles only two of which address this model of grief reaction in direct relationship to the specific experience of loss of a fetus or infant. These

are reasonably low results. There is little linking perinatal loss and the Kubler-Ross model of grief. It is not supported by research in this arena and therefore cannot be practiced as an evidence based intervention or therapeutic tool.

Swanson's Theory of Caring upholds the following tenets: Maintaining Belief, Knowing, Being With, Doing for and Enabling (Kavanaugh, 2015). Swanson collected data from couples experiencing a miscarriage, couples with babies in the NICU and parents who had been given an unexpected fetal diagnosis. The outcome of her work led to the Theory of Caring (Kavanaugh, 2015). This theory has been generalized to broader populations and taught as apart of nursing school curriculum. Reading into the studies that Swanson developed this theory from brings forward insights and observations from patients lived expressions of grief. Their stories provide tangible data for care providers to consider when looking after bereaved families. For example, identifying when and how patients felt cared for in these settings may help in shaping a foundation for developing tools to support the grief, mourning and healing of individuals and families as they integrate loss into their lives.

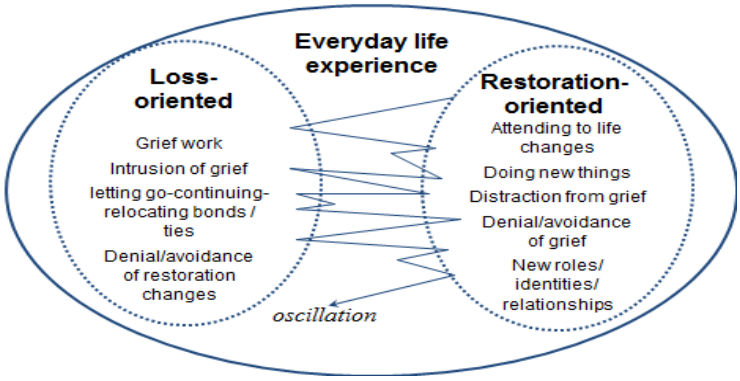
Attachment Theory and Continuing Bonds

To understand grief that follows loss, it is important to have a clear picture of attachment theory in the setting of grief specifically. When a fetus or infant dies, the perceived connection by the parent(s) can be a driving force in the bereavement outcomes. An expectation of connection during pregnancy can be the beginning of attachment. When a fetus dies unexpectedly or is diagnosed unexpectedly with a life-threatening condition, loss is compounded by unmet expectations and under-actualized attachment. (Price et al., 2016). Attachment theory of grief posits two phases to the process: protest and despair. (Lichtenthal et al., 2016). We

memorialize the dead, and thereby make meaning of their dying in the places we lay them to rest, in their former belongings, a hat, a photograph, the matching pajamas. As these objects eventually fall short and the loss becomes the reality, a sense of despair sets in. In perinatal loss, this type of meaning-making can complicate the grief process as there may not be a physical object to memorialize the lost life or the lost imagination of a life unlived. When families find meaning in their continued connection to their loved one who died, they seem to cope better and to have a more integrated grief experience. (Lichtenthal et al., 2016). Relationships change significantly but are not severed at death.

Another important model of coping is the Dual Process Model (DPM), conceptualized by researchers Margaret Stroebe and Henk Schut. It was developed to specifically highlight the dynamic process of coping associated with bereavement. (Fasse and Zech, 2016). Their model addressed concerns that prevail today involving unclear definitions with little evidence or validated research to support the models employed in healthcare settings. The DPM focuses on two types of coping. Loss Oriented coping applies to direct stress, grief or mourning associate with the acute loss. Restoration Oriented coping refers to the way the bereaved person adapts to stressors, creates new meaning and capacity secondary to the loss itself and as a part of their new identity. There is no specific road map for navigating these two mainstays of coping. They are dynamic states of being that the bereaved navigate.

Figure 1. The Dual Process Model, Dynamic Oscillation (Stroebe, Schut, 1999).



An important distinction addressed in the DPM is that the process of dynamic oscillation is perceived as adaptive. (Fasse and Zech, 2016). Grief is not stagnant, nor is it linear, moving progressively from one stage to the next. The Dual Process Model indeed provides a more dynamic, lively, interpretation of adaptation by the bereaved person. It therefore has great therapeutic potential allowing for the nuances of human experience. Stroebe and Schut's concern for offering a more relevant model of coping loss proves strong. Their criticism of imprecise definitions remains an issue in the context of perinatal bereavement.

Discussion

The healthcare field relies heavily on clear and direct communication. Discrepancies in theoretical definitions can be problematic if not dangerous. Without an agreed upon conceptual framework it is difficult to establish interventions that may influence positive outcomes in the lives of bereaved parents. The literature suggests that often bereavement in the perinatal setting has been operationalized interchangeably with grief and mourning (Stunkard, 2009). There are

few descriptions that adequately address the complexity of the phenomenon of perinatal bereavement.

A principle based concept analysis authored by Albert J. Stunkard, MD, identifies four modes of understanding the concept of perinatal bereavement; epistemological (is it well defined and well differentiated?), pragmatic (is it significant and useful?), linguistic (is there consistency in use and meaning) and logical (how does it uphold boundaries through theoretical integration?) (Stunkard, 2009). The authors present these four modes to help researchers and practitioners work towards a theoretical definition to more appropriately operationalize the concept of bereavement. Grief is often identified as the main attribute of perinatal bereavement, accompanied by complex expressions such as depression all influenced by external circumstances when the loss occurs. (Stunkard, 2009). A significant contribution that this definition of bereavement appears to pull apart is that grief research has not encompassed the anticipation of a loss which may occur for example in the event of an unexpected fetal diagnosis and the choice to terminate. (Stunkard, 2009). That bereavement may begin before a loss has fully taken place broadens the umbrella. The diagnosis of a life threatening or life limiting condition is a loss in its own right. It can be the loss of a life imagined that causes a process of grieving. The insights offered in this publication are corroborated by the narratives and qualitative analyses of peer researchers.

Honoring patient values and autonomy in the face of loss is vital. Although a family may not have the child they always wanted, they may have the opportunity for the quality of care and support through the process of childbirth that they had envisioned. (Weatherby & Bywater, 2011). The ideal outcome of childbirth is a healthy baby and a healthy mother. When one is not possible, we must honor the continued importance of the other. How babies are born matters to

the health of the baby and the psychological well-being of the parents. Whether parents choose a low intervention birth or a high intervention birth, and this is no different in a time of unexpected outcome, autonomy plays a role in well-being. (Dimiceli-Zsigmond et. al, 2015)

Conclusion

This paper discusses a variety of theories related to grief and bereavement. The purpose of perinatal bereavement research is to establish a more cohesive utilization of the concept and care practices associated with perinatal loss. When the concept of perinatal bereavement is made uniform and comprehensive it can be operationalized to enhance research efforts and inform implementation for better practice. The goal of enhancing care during unexpected losses and diagnoses during the perinatal period is to support women, partners and families as they navigate their losses. Bereavement can be nuanced and therefor poses challenges to a healthcare system that is built around diligent science and evidence, a system that works to save lives sometimes at any cost. Death and the emotional integration of loss poses a complex challenge and unique opportunity to provide care based in autonomy and dignity. Arielle's birth story illuminates the mosaic of grief and adaptation represented across many different grief theories. Most notably her emphasis on the value of having a birth experience that resembled what she had originally hoped for in the face of her unexpected loss. Her story is a testament to the importance of understanding the meaning of the loss to the bereaved individual and the imperative to provide care that values that meaning.

Recommendations for Further Research

After review of the current literature, it is evident that interventions regarding perinatal bereavement need further research. Topics that may also add to this growing body of research include African American women or Latina women's experiences of perinatal loss and fathers' and partners' experiences of perinatal loss. Deeper examination of these areas will serve as an important contribution to the understanding of perinatal bereavement.

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